

Consumer Committee
2007-2008 Year-End Report
June 2008

Drafted for the
Boston Part A EMA
HIV Health Services
Planning Council

Produced by



1010 Massachusetts Avenue, 2nd Floor
Boston, MA 02118
www.bostonplanningcouncil.org

*The Consumer Committee of the Boston EMA HIV Health Services Planning Council
presents its 2007-2008 Year-End Report*

Committee Charge

The Consumer Committee is one of the Planning Council's standing committees. The Planning Council's bylaws state the charge to the committee at Section 6.4.6:

“The Consumer Committee shall ensure that people living with HIV and/or AIDS are empowered, supported, and encouraged to work on the full range of activities that the Planning Council undertakes in the execution of its mandate, by:

- A) Fostering and developing consumer leadership;
 - B) Working with the Executive Committee to ensure that at least one Consumer is on each Planning Council committee;
 - C) Informing the Planning Council on issues from a consumer perspective, as needed; and
 - D) Ensuring that diverse consumer input and participation are included in all Planning Council and committee activities.”
-

Committee Membership

Members

Arthur Weeks, Chair
Madeline Pagan, Vice-Chair
Richard Berryman
Diane Hackett
Sandra Newton
Brian Quigley
Iris Rivera
Osvaldo Rivera
Shirley Royster
Florence Saintiche
Constance Santiago
Van Thomas

Staff

Michael Hager, PCS
Steph Sharp, PCS
Leela Strong, PCS
Frantzou Balthazar, BPHC

Committee Meetings

Thursday, October 11, 2007	2:00pm-3:30pm	Boston Public Library
Thursday, November 8, 2007	2:00pm-3:30pm	Boston Public Library
Thursday, January 10, 2008	2:00pm-3:30pm	Boston Public Library
Thursday, February 14, 2008	2:00pm-3:30pm	Boston Public Library
Thursday, March 13, 2008	2:00pm-3:30pm	Boston Public Library
Thursday, April 24, 2008	2:00pm-3:30pm	Boston Public Library
Thursday, May 8, 2008	2:00pm-3:30pm	Boston Public Library
Thursday, June 12, 2007	2:00pm-3:30pm	Boston Public Library
Thursday, June 26, 2007	2:00pm-3:30pm	Boston Public Library

Work of the Committee

Consumer Committee is unique among the Planning Council committees in that it has no assigned membership and its leadership is not selected by the Planning Council Chair. Instead, all Planning Council members living with HIV and parents with HIV-positive children are welcome to attend Consumer Committee meetings. The Chair and Vice-Chair are elected by the Consumer Committee members at their first meeting. Consumer Committee meets for ninety minutes before each Planning Council meeting.

Consumer Committee has two main functions. First, Consumer Committee acts as a place for Planning Council members living with HIV to preview Planning Council presentations. Second, Consumer Committee provides people living with HIV a place to share their personal and community experience as it relates to Planning Council issues.

Consumer Training

Planning Council consumers were asked to assess their training needs through a survey at the beginning of the Planning Council term. The following trainings were provided this Planning Council term:

- ***Epidemiology***
October 11, 2007
Assist Planning Council members in understanding basic epidemiological concepts including data sources, uses, collection and basic epidemiological terms.
- ***Meeting Facilitation and Leadership Skills training (Part 1)***
January 10, 2008
Empower Planning Council members to take part in leadership and decision making process.
- ***Needs Assessment and Using Public Health Data***
March 13, 2008
Assist Planning Council members in understanding the Needs Assessment process including; using public health data sources, data collecting and identifying the needs of people living with HIV/AIDS. An overview discussion of the most recent Needs Assessment was included in the training.
- ***Priority Setting***
March 13, 2008
Educate Planning Council member on the Priority Setting Exercise and discuss its role in the Planning Council process.
- ***Meeting Facilitation (Part 2)***
March 26, 2008
Delivered in response to requests for more training at Meeting Facilitation (Part 1) this training was delivered by Maria Orsini and Beth Hastie of JRI Health.
- ***Resource and Allocations Process***
April 24, 2008
Assist Planning Council members in understanding the role of the Resource and Allocations Committee and their work as part of the Planning Council Cycle.
- ***Public Funding for HIV/AIDS Care and Support Services in the Boston EMA***
May 8, 2008

Assist Planning Council members in understanding various public funding sources for HIV/AIDS care in the Boston EMA and the types of services provided by these funding sources. Also assists members in understanding how Funding Streams data interplays with the Planning Council's Resource & Allocations process.

- ***Computer Skills Training***

- Ongoing

- Computer skills trainings were provided to participants in the Consumer Laptop Program (CLP) upon request. Most participants were familiar with computers. Three applicants requested computer training this term.

All training programs are being reviewed by PCS staff for updates and revisions over the summer interim. Planned improvements include interactive Computer Training, updated HIV101 and 102 modules and epidemiology modules, as well as online training materials.

Consumer Reimbursement Program

Consumer members of the Planning Council are eligible for reimbursement for certain expenses associated with their participation. These expenses include; childcare, parking, travel, and conferences.

Consumer Laptop Program (CLP)

CLP provided laptop computers, printers, an AOL account and technical assistance to consumer members of the Planning Council upon request. The CLP aims to provide an equal level of information access for all Planning Council members in addition to improving the line of communication between the Planning Council, PCS, and BPHC.

The CLP currently consists of ten laptop computers, all of which were loaned to current Planning Council consumers and two additional laptop computers are available for use. Twelve Planning Council consumers hold AOL accounts provided through CLP.

Liaison with Policy Committee

The Consumer Committee Chair Arthur Weeks worked with Policy Committee member and consumer Florence Saintiche to provide timely updates on pressing policy developments to the Consumer Committee. Consumer Committee conversation and questions related to these policy issues were then taken back to Policy Committee for answers and to provide a consumer-centered compass to Policy Committee research.

Consumer Committee Meeting Activities

- **Thursday, October 11, 2007**

- The meeting included an assessment of Planning Council consumer training needs. Arthur Weeks was elected Chair of the Consumer Committee and Madeline Pagan was elected Vice-Chair. Epidemiology training was conducted. The agenda for the October

11, 2007 Planning Council meeting was reviewed; the meeting's presentations were also reviewed.

- **Thursday, November 8, 2007**

The meeting included review of Consumer Committee needs for the 2007-2008 Planning Council term. The agenda for the November 8, 2007 Planning Council meeting was reviewed; the meeting's presentations were also reviewed.

- **Thursday, December 13, 2007**

This meeting was cancelled due to a weather emergency.

- **Thursday, January 10, 2008**

The agenda for the January 10, 2008 Planning Council meeting was reviewed; the meeting's presentations were also reviewed. Training on meeting facilitation was conducted.

- **Thursday, February 14, 2008**

The agenda for the February 14, 2008 Planning Council meeting was reviewed; the meeting's presentations were also reviewed. Consumers participated in revising the Standards of Care.

- **Thursday, March 13, 2008**

The agenda for the March 13, 2008 Planning Council meeting was reviewed; the meeting's presentations were also reviewed and training on the Needs Assessment and Priority Setting processes were conducted.

- **Thursday, April 24, 2008**

The agenda for the April 24, 2008 Planning Council meeting was reviewed; the meeting's presentations were also reviewed. Resource and Allocations process training was presented. Consumers also participated in a Strategic Planning Exercise for next year's term.

- **Thursday, May 8, 2008**

The agenda for the May 8, 2008 Planning Council meeting was reviewed; the meeting's presentations were also reviewed. Consumers developed recommendations for their 2007-2008 Year-End Report and practiced conducting a vote during a meeting.

- **Thursday, June 12, 2008**

The agenda for the June 12, 2008 Planning Council meeting was reviewed; the meeting's presentations were also reviewed. Consumers drafted their Year-End Report.

- **Thursday, June 26, 2008**

The agenda for the June 26, 2008 Planning Council meeting was reviewed; the meeting's presentations were also reviewed. Consumers practiced delivering the Year-End Report.

Progress on Recommendations from 2006-2007 Consumer Committee

1. Standardize Committee membership – The possibility of standardized membership was examined for the 2007-2008 term but if membership were standardized, consumers would either be required to sit on two committees or if consumer members attended only Consumer Committee, there would be lower representation on the other committees. Neither solution seemed desirable, so the Consumer Committee elected to keep membership optional for this term.
2. Cross Committee Reporting – Florence Saintiche served as the liaison to Policy Committee and Consumers were invited to attend several Evaluation Committee events to add additional consumer voices to evaluation projects. Additionally, Arthur Weeks

participated in the Bylaws Committee meetings and the Committee was given the opportunity to make recommendations to the Resource and Allocations Committee.

3. Split training and community sharing functions – Several training were held outside of the Committee this year including meeting participation and facilitation and laptop training. During Consumer Committee meetings, the training function was concentrated to allow for the discussion of more pertinent material and to allow more time for community concerns.
4. Presenters have materials available for review – Presentation materials were condensed to fit in the abbreviated format of Consumer Committee. This year every presentation was accompanied with a handout.
5. Increase consistency of presentations – By the end of the term, a four slide format was developed for handouts to cover the key points and presenters were asked to cover
 - i. The reason for the presentation
 - ii. Its relation to the Planning Council Cycle
 - iii. The main points and objectives

These points could be covered in 10-30 minutes depending on the availability of time in the agenda.

6. Continue Consumer Reimbursement Program – This program was continued with a revised reimbursement system that allowed for improved financial tracking and faster turnaround at Council meetings.
7. Improve Consumer Laptop Program (CLP) The purpose of the CLP is to ensure all Planning Council members have equal access to materials and learning opportunities. Since high speed internet is not available in all areas of the EMA, reimbursement for high speed internet was not provided. However, to increase usability of the machines, laminated sheets were provided which detailed the capabilities of each machine.

Recommendations to the 2008-2009 Consumer Committee

1. The Consumer Laptop Program should continue to be offered to all consumer members of the Council, but priority should be given to active members of the Consumer Committee.
2. Laptops should be replaced or improved; current machines are inadequate to support the basic needs of Consumers.
3. A summary sheet of Council meetings should be available so that members whose primary language is not English can know what the main points of the meeting are. This would also serve as a starting point should translation services be needed.
4. Continue the training survey at the start of each term.
5. Suggestions for future trainings include: HIV Health Vocabulary Training; Co-infection with HCV; Complementary Therapies; HIV/AIDS Services and Clinical Trials in the Boston EMA; New and Upcoming Services and Treatments; Initiatives in the HIV/AIDS Field; Managing Side Effects and Treatment; Mental Health and Substance Abuse Services Training.